



# Enrolment and retention of people who inject drugs in the Needle & Syringe Exchange Programme in Malaysia

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**Setting:** Needle and Syringe Exchange Programme (NSEP) implemented by non-governmental organisations in Malaysia.

**Objectives:** To determine enrolment, characteristics and retention in the NSEP of people who inject drugs (PWID) between 2013 and 2015.

**Design:** Retrospective cohort study.

**Results:** There were 20946 PWID, with a mean age of 38 years. The majority were male (98%) and of Malay ethnicity (92%). Follow-up data were available for 20761 PWID. Annual retention of newly enrolled PWID for each year was respectively 85%, 87% and 78% for 2013, 2014 and 2015, although annual enrolment over these years declined from 10724 to 6288 to 3749. Total person-years (py) of follow-up were 27806, with loss to follow-up of 40 per 100 py. Cumulative probability of retention in NSEP was 66% at 12 months, 45% at 24 months and 26% at 36 months. Significantly higher loss to follow-up rates were observed in those aged 15–24 years or ≥50 years, females, transgender people and non-Malay ethnic groups.

**Conclusion:** Annual retention of new PWID on NSEP was impressive, although enrolment declined over the 3 years of the study and cumulative loss to follow-up was high. A better understanding of these programmatic outcomes is required.

Human immunodeficiency virus (HIV) transmission through injecting drug use is a significant driver of the HIV epidemic in many countries.<sup>1</sup> Globally, injecting drug use accounts for a third of new HIV infections outside sub-Saharan Africa,<sup>2</sup> with the highest drug-related incidence occurring in Asia and Eastern Europe.<sup>2,3</sup> Of the 16 million people who inject drugs (PWID) worldwide, 3 million are HIV-positive.<sup>4</sup> The most recent data from 49 countries show that HIV prevalence rates among PWID are 20–50 times higher than in the general population.<sup>5</sup> The Asian region is particularly affected, with some cohorts reporting an HIV prevalence of up to 20–28% among PWID.<sup>2,3</sup>

The introduction of the Needle & Syringe Exchange Programme (NSEP) has played a significant role in reducing the global HIV burden.<sup>6,7</sup> NSEP is recommended for implementation globally as a critical component of a comprehensive package of nine harm reduction interventions, as it reduces the injecting risk associated with HIV and other blood-borne infectious diseases such as hepatitis viruses B and C.<sup>6,8</sup>

Malaysia, a country in South-East Asia with a concentrated HIV epidemic, has a high HIV infection rate

among its estimated 170000 PWID.<sup>9</sup> Malaysia's National Strategic Plan on HIV/AIDS (acquired immune-deficiency syndrome) is committed to fast-tracking the national HIV response.<sup>10</sup> There was a shift from punitive law enforcement approaches to evidence-based treatment,<sup>11,12</sup> and harm reduction programmes are a key component of the plan, with particular focus on NSEP and Methadone Maintenance Therapy (MMT).<sup>10</sup> The NSEP is implemented through both government health clinics as well as non-governmental organisations (NGOs). By the end of 2015, a total of 99824 PWID were accessing the NSEP nationwide.<sup>13</sup> These were mostly male and of Malay ethnicity.<sup>14</sup>

Despite the impressive enrolment of PWID into the NSEP, little is known about retention in NSEP and the characteristics of PWID associated with loss to follow-up (LTFU). This information is important. For the individual client, long-term retention in the NSEP may moderate the frequency of injection<sup>15</sup> and may reduce the acquisition or transmission of HIV and other viruses such as hepatitis B and C.<sup>16</sup> Knowing who is enrolled and subsequently retained in a programme is essential for cost-effective forecasting and procurement of syringes, needles and other consumables; planning of logistics and human resource needs; and progressive quality and outcome improvement.

The present study was therefore undertaken to document the enrolment, characteristics and retention in care of PWID within an NGO-implemented NSEP in Malaysia from 2013 to 2015.

## METHODS

### Study design

This was a retrospective cohort study.

### Setting

#### General setting

Malaysia, in South-East Asia, is composed of two distinct geographical regions separated by the South China Sea, Peninsular Malaysia and Malaysian Borneo (East Malaysia),<sup>17</sup> and consists of 13 states and three federal territories. Malaysia has a population of 31 million. The largest ethnic groups are the Malays (50%), followed by the Chinese (24.6%) and the Indians (7.3%). The Sabahan and Sarawakian, in Malaysian Borneo, constitute 12% of the population.<sup>17</sup>

#### Specific setting: HIV/AIDS and NSEP

Malaysia's HIV epidemic is concentrated among several key populations. HIV prevalence is as follows:

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### KEY WORDS

operational research; harm reduction; SORT IT; loss to follow-up; risk factors

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	STATE	NGO
●	Kedah	Cahaya Harapan
●	Pulau Pinang	AIDS Action & Research Group
●	Perak	Pertubuhan Komuniti Intan
●	Kuala Lumpur	Persatuan Kebajikan Komuniti Ikhlas
●	Selangor	Persatuan Insaf Murni Malaysia
●	Negeri Sembilan	Kelab Sahabat Meta
●	Melaka	Projek Rintis NSEP & MMT Melaka
●	Johor	Intan Life Zone
●	Pahang	Komited Malaysia
○	Terengganu	Cakna
●	Kelantan	SAHABAT

**FIGURE 1** Map of Malaysia with location of programme sites. NGO = non-governmental organisation.



transgender people (5.6%), female sex workers (7.3%), men who have sex with men (8.9%) and PWID (16.3%).<sup>13</sup> Since the first AIDS case was reported in 1986, over 105 189 people have been diagnosed with HIV and 21 384 with AIDS, and 17 096 AIDS-related deaths have been recorded to date. There are currently 88 093 people living with HIV nationally. Despite the high burden of infection and disease, progress is being made: the HIV notification rate in Malaysia declined from 28.4 per 100 000 population in 2002 to 10.9 in 2009, although rates have remained at this level for the past 5 years.<sup>9</sup>

Given the importance of injecting drug use as the main driver of Malaysia's HIV epidemic, NSEP and MMT have gained prominence within the national HIV response. In 2006, the NSEP started to provide PWID with clean needles and syringes, and then treatment and care services for those in need. By 2014, 78% of the NSEP services were provided by NGOs, while the remaining 22% were provided by government health clinics.<sup>9</sup>

#### **NSEP implemented and monitored in the NGO setting**

The Ministry of Health channels funds to a national NGO, the Malaysian AIDS Council, which apportions the funds and provides capacity building, technical support and coordination to other NGOs, civil society and community-based organisations involved in the HIV response in the country. In 2015, the Malaysian AIDS Council supported 11 NGOs in implementing the NSEP in 20 fixed sites across 11 states in Peninsular Malaysia (Figure 1).

The NGO-NSEP is implemented through an outreach model. Outreach workers, who are former drug users and/or people enrolled in the MMT, distribute clean needles and syringes in exchange for used ones to clients in the community, while providing them with information on safe injecting practices, safe sex and HIV. Clients are defined as 'enrolled' on first contact with outreach workers and acceptance of the services. Clients are provided with clean needles every 2 weeks by outreach workers, and bimonthly appointments are

made to meet them at the same locations. Attempts are made to find clients who miss their appointments. To facilitate individual follow-up and confidentiality, each client is assigned a unique identifier code at enrolment into the NSEP. If clients have not been seen for  $\geq 6$  months, they are classified under LTFU.

During community outreach sessions, the outreach workers collect programmatic service data using simple, pocket-sized data collection logbooks. These data include demographic characteristics, date of last contact with the client, needles and syringes distributed, educational materials provided and future appointment dates for routine NSEP or specific services such as HIV screening. Service data are transferred from the outreach logbooks to paper-based registers every day by programme coordinators at the 20 sites. Programme coordinators then enter these on a weekly basis into an electronic database (SyrEx, Kiev, Ukraine) developed by the International HIV/AIDS Alliance (Hove, UK) in 2012. Site data are then reported to the Malaysian AIDS Council (Kuala Lumpur, Malaysia) on a monthly basis and aggregated for routine reporting to the Ministry of Health (Putrajaya, Malaysia).

#### **Study population**

The study included all PWID enrolled in the NGO-NSEP between 1 January 2013 and 31 December 2015. Clients with no recorded first date of enrolment were excluded. PWID enrolled in 2012 were also excluded, as the Syrex electronic database used for data recording was only introduced in the second quarter of that year.

#### **Data variables, source of data and data extraction**

Data variables include date of enrolment, client unique identifier, sex, age, ethnic group, implementing NGO and last date of recorded contact. These data were extracted from the Syrex electronic database at the Malaysian AIDS Council between March and September 2016 and exported to Microsoft Excel (Microsoft, Redmond, WA, USA).

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**TABLE 1** Demographic characteristics of all clients ever enrolled in the NSEP in Malaysia between January 2013 and December 2015

Characteristics	n (%)
Total client population	20 964
Age group, years	
15–24	926 (4)
25–39	12 151 (58)
40–49	5 986 (29)
≥50	1 883 (9)
Sex	
Male	20 564 (98)
Female	344 (2)
Transgender	38 (<1)
Ethnic group	
Malay	19 338 (92)
Chinese	614 (3)
Indian	595 (3)
Sarawakian	232 (1)
Sabahan	17 (<1)
Other	150 (1)
Implementing NGO	
Komited Malaysia	4 615 (22)
Cakna	2 874 (14)
Sahabat	2 463 (12)
Intan Life Zone	2 320 (11)
Cahaya Harapan	2 253 (11)
Persatuan Kebajikan Komuniti Ikhlas	1 732 (8)
Kelab Sahabat Meta	1 609 (7)
Persatuan Insaf Murni Malaysia	1 225 (6)
Pertubuhan Komuniti Intan	963 (5)
AIDS Action & Research Group	756 (4)
Projek Rintis NSEP & MMT Melaka	136 (<1)

NSEP = Needle & Syringe Exchange Programme; NGO = non-governmental organisation; AIDS = acquired immune-deficiency syndrome; MMT = methadone maintenance therapy.

### Analysis and statistics

The main outcomes analysed were retention in the programme and LTFU from the programme censor date, i.e., 31 December 2015. If a client had not been seen in the programme for 6 months, he/she was classified under LTFU at the 6-month date. At the end of each year, the number of PWID enrolled in that year along with the numbers retained/recorded as LTFU at that time was calculated.

LTFU rates were calculated by dividing the number of clients recorded under LTFU by total person-years (py) of follow-up. Characteristics associated with LTFU were analysed using the Cox proportional hazard model. Levels of significance were set at 5%. Factors associated with LTFU with  $P < 0.05$  were adjusted. Finally, the probability of retention in the programme was plotted using the Kaplan-Meier survival curve, which takes into account that LTFU could only be recorded if a client had not been seen for ≥6 months. EpiData version 2.2.2183 (EpiData Association, Odense, Denmark) was used for descriptive statistics and STATA version 14 (Stata Corps, College Station, TX, USA) was used to perform survival and time to event analysis.

### Ethics

Permission to use the data was obtained from the Ministry of Health, Putrajaya, and the Malaysian AIDS Council, Kuala Lumpur, Malaysia. Ethics approval was obtained from the Ethics Advi-

sory Group of the International Union Against Tuberculosis and Lung Disease, Paris, France, and the Human Research Ethics Committee, Universiti Sains Malaysia, Penang, Malaysia.

## RESULTS

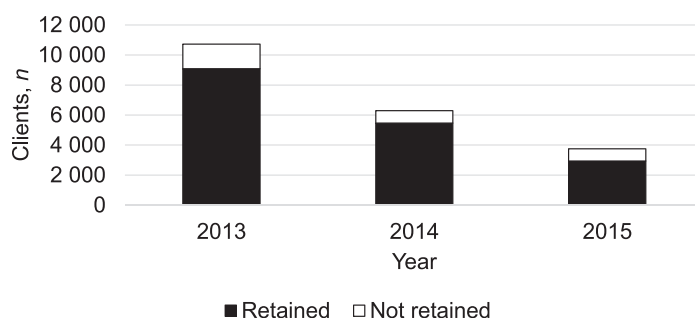
Between 2013 and 2015, 20 946 PWID were enrolled into the NSEP. Their characteristics are shown in Table 1. The mean age was 38 years (standard deviation 8.4); the majority were male and of Malay ethnicity. Komited Malaysia (Kuantan, Malaysia) was the implementing NGO with the highest number of PWID.

There were inconsistent dates in 185 PWID records; data on 20 761 PWID were therefore analysed for retention and LTFU. Figure 2 shows the number of new PWID enrolled each year. Numbers enrolled each year declined from 10 724 to 6 288 to 3 749. Of the PWID newly enrolled each year, the percentage retained at the end of the year was respectively 85%, 87% and 78%. The cumulative probability of retention in care for all individual PWID enrolled over the 3 years is shown in Figure 3; it was 66% at 1 year, 45% at 2 years and 26% at 3 years.

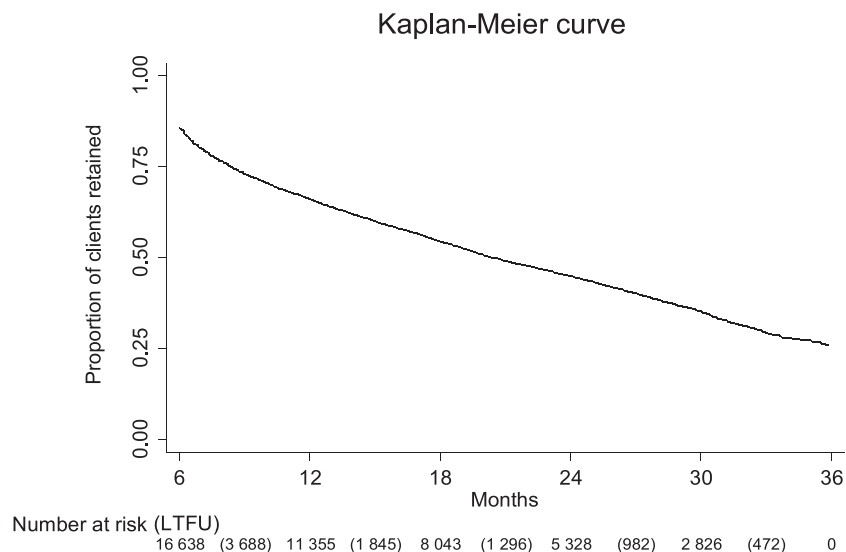
Cumulative LTFU at the end of 2015 was 11 051 (53%). Total py follow-up were 27 806; the LTFU rate was 40/100 py follow-up. LTFU rates in relation to baseline characteristics are shown in Table 2. Being aged 15–24 years or ≥50 years, female or transgender, Chinese, Indian, Sarawakian or of another ethnic group were significantly associated with higher LTFU rates in unadjusted and adjusted analysis. Age ≥50 years and Chinese ethnicity did not remain predictive in adjusted analyses. Compared with the largest implementing NGO (Komited Malaysia), all other NGOs had significantly higher LTFU rates in both unadjusted and adjusted analysis, except for Project Rintis NSEP and MMT Melaka (the latter only started NSEP activities from April 2015).

## DISCUSSION

This is the first study in Malaysia to assess enrolment, retention and risk factors for LTFU in PWID managed within the NGO sector. There were some interesting findings. First, the cumulative enrolment of over 20 000 PWID in the 3 years and the proportion of newly enrolled PWID retained at the end of each year was impressive, at respectively 85%, 87% and 78%. However, there was an annual decline in enrolment of about 40% from one year to the next. As the NGO-NSEP was started in 2006 and initially recorded high enrolment numbers (55 298 PWID were reached through this programme between 2006 and 2012), it is possible



**FIGURE 2** Number of clients enrolled and retained in care in the Needle & Syringe Exchange Programme in Malaysia between 2013 and 2015. The stacked bars show new clients enrolled each year and the number of new clients who are retained in the programme at the end of the year.



**FIGURE 3** Probability of being retained in care\* for clients enrolled into the Needle & Syringe Exchange Programme in Malaysia between 2013 and 2015. \*Clients who were in the programme for  $\leq 6$  months were regarded as having been retained because LTFU was defined as not being seen for  $\geq 6$  months. LTFU = loss to follow-up.

that by now there is good countrywide coverage reaching saturation and a change in the pattern of risk behaviour among PWID. Other reasons might include PWID being referred to MMT. This is supported by the increasing number of PWID being enrolled in the MMT programme nationwide.<sup>13</sup> Komited Malaysia was the best performing NGO, possibly because it acted as a one-stop HIV care centre, offering comprehensive services from prevention to treatment and care, as well as shelter homes and drop-in centres, thus encouraging better retention rates amongst its clients.

Second, only 2% of PWID were female, consistent with the findings of the Integrated Biological and Behavioural Surveillance Survey 2012, which suggests that PWID in Malaysia are predominantly male.<sup>14</sup> More than 90% of PWID were also of Malay ethnicity, possibly because the programme was able to reach out more to the Malay population, which constitutes 50% of the Malaysian population.

Third, cumulative retention at the end of 3 years was under 50%. There is a scarcity of published studies on this subject, with one study in Baltimore, MD, USA, reporting a 12-month retention rate of 64%.<sup>18</sup> The programme recognises several reasons for LTFU, including formal or self-referral to MMT programmes, leaving the NSEP because of stopping injecting drug use, leaving the area and failing to re-register elsewhere, and incarceration. In addition, PWID have a higher risk for HIV and other infections that may increase their mortality.

Finally, several factors were associated with a higher risk of LTFU. From the client perspective, PWID aged 15–24 or  $\geq 50$  years were at very high risk of LTFU, a finding consistent with other studies showing higher LTFU rates in younger PWID.<sup>19,20</sup> Younger PWID may be more mobile, with fewer sources of money for drugs, and they may also not appreciate the value of the services provided through the NSEP.<sup>21</sup> They also have a higher probability of being incarcerated.<sup>18</sup> In the older age group, different reasons probably prevail, including a higher likelihood of comorbidities, another area in need of qualitative research. The higher LTFU rates among female or transgender PWID may reflect the design of the pro-

gramme, where <10% of outreach workers are female and transgender. The needs of women who inject drugs are different from those of men,<sup>22</sup> and their service utilisation may be highly influenced by their sexual partners.<sup>23</sup> These sex-specific factors should be taken into account to ensure that NSEP interventions effectively address the unique needs of women who inject drugs. Ethnicity is an important mediator of injecting risk behaviour,<sup>24</sup> and in our study ethnic groups other than Malay were not only poorly represented in the programme, they also had higher LTFU rates.

There were several strengths to this study. The study population was large and there was a long period of follow-up compared with other studies that have examined retention in care.<sup>18,25</sup> The study was also reported according to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.<sup>26</sup>

However, there were a number of limitations. First, we only analysed data from PWID enrolled under NGO-NSEP, and the results may not be representative of NSEP in government settings. Second, as we included only PWID with a first date of contact in the original database, not all clients were included. Third, we limited the study period to 2013–2015, although the NSEP was started in 2006. This was because of the introduction of the electronic database in 2012, which made it easier to track PWID within the programme compared with when paper-based registers were used. Fourth, we had only a few demographic characteristics with which to assess risk factors for LTFU, whereas others, such as smoking, alcohol, social and economic circumstances or incarceration history, would have provided a richer and deeper analysis. Finally, the study was based on routinely collected programme data, and there may have been transcribing errors in data recording and data entry.

In conclusion, this study shows that despite impressive yearly retention of PWID and a large number of PWID cumulatively enrolled into the NGO-NSEP between 2013 and 2015, the annual numbers enrolled have declined from year to year, there is a large cumulative LTFU rate and there are certain demographic charac-



**TABLE 2** Factors associated with clients being recorded as LTFU in the NSEP in Malaysia between January 2013 and December 2015

Characteristics	Enrolled* <i>n</i>	LTFU† <i>n</i>	LTFU rate‡ /100 py	HR (95%CI)	aHR (95%CI)
Total	20 761	11 051	40	—	—
Age group, years					
15–24	916	520	50	1.3 (1.2–1.4)§	1 (0.8–1.1)
25–39	12 049	6 353	40	Reference	
40–49	5 932	3 061	37	0.9 (0.9–1.0)§	1 (0.9–1.1)
≥50	1 864	1 117	47	1.2 (1.1–1.3)§	1.5 (1.3–1.7)§
Sex					
Male	20 387	10 792	39	Reference	Reference
Female	336	229	61	1.6 (1.4–1.8)§	1.9 (1.5–2.5)§
Transgender	38	30	86	2.3 (1.6–3.4)§	3.2 (1.4–7.1)§
Ethnic group					
Malay	19 175	10 039	39	Reference	Reference
Chinese	605	330	46	1.2 (1.1–1.4)§	1 (0.8–1.1)
Indian	586	361	53	1.3 (1.3–1.5)§	1.2 (1.0–1.5)§
Sarawakian	231	180	76	2.1 (1.8–2.4)§	2.8 (2.0–3.8)§
Sabahan	17	10	33	0.8 (0.4–1.5)	1.7 (0.6–4.5)
Other¶	147	131	64	1.7 (1.4–2.0)§	5.3 (3.2–9.0)§
Implementing NGO					
Komited Malaysia	4 589	1 684	26	Reference	Reference
Cakna	2 851	1 356	33	1.3 (1.2–1.4)§	1.6 (1.4–1.7)§
Sahabat	2 438	1 498	44	1.7 (1.6–1.9)§	2.7 (2.5–3.0)§
Intan Life Zone	2 314	1 160	32	1.2 (1.1–1.3)§	1.6 (1.5–1.8)§
Cahaya Harapan	2 225	1 582	65	2.7 (2.5–2.9)§	4.2 (3.8–4.7)§
Persatuan Kebajikan Komuniti Ikhlas	1 713	1 063	56	2.4 (2.2–2.6)§	2.5 (2.2–2.8)§
Kelab Sahabat Meta	1 599	1 017	46	1.8 (1.7–2.0)§	2.9 (2.5–3.2)
Persatuan Insaf Murni Malaysia	1 212	570	34	1.3 (1.2–1.4)§	1.4 (1.2–1.6)§
Pertubuhan Komuniti Intan	939	746	87	3.7 (3.4–4.0)	6.6 (5.6–7.8)§
AIDS Action & Research Group	745	375	38	1.5 (1.4–1.7)§	1.5 (1.3–1.8)§
Projek Rintis NSEP & MMT Melaka	136	0	—	—	—

\*Includes all clients enrolled in the programme between January 2013 and December 2015 with recorded first date of contact.

†Includes clients who were not seen in the programme for ≥6 months.

‡100 py of follow-up.

§*P* < 0.001.

¶Includes foreigners and other minority ethnic groups.

LTFU = loss to follow-up; NSEP = Needle &amp; Syringe Exchange Programme; py = person-years; HR = hazard ratio; CI = confidence interval; aHR = adjusted HR; NGO = non-governmental organisation; AIDS = acquired immune-deficiency syndrome; MMT = methadone maintenance therapy.

teristics associated with higher rates of attrition from care. Reasons for the LTFU need to be better understood. The programme would benefit from 1) using its electronic database to expand the set of baseline variables to better characterise newly enrolled PWID, 2) establishing a programme of operational and qualitative research to help answer many of the questions raised from this study, and 3) linking up with the MMT programme to understand whether drop-outs from the NSEP in fact represent referral and entry to another important support service.

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**Contexte :** Programme d'échange d'aiguilles et de seringues (NSEP) mis en œuvre par des organisations non-gouvernementales en Malaisie.

**Objectif :** Déterminer l'enrôlement, les caractéristiques et la rétention dans le NSEP des personnes qui s'injectent des drogues (PWID) entre 2013 et 2015.

**Schéma :** Etude rétrospective de cohorte.

**Résultats :** Il y a eu 20 946 PWID, dont l'âge moyen a été de 38 ans. La majorité a été de sexe masculin (98%) et d'ethnie malaise (92%). Les données de suivi ont été disponibles pour 20 761 PWID. Le taux de rétention annuel des PWID nouvellement enrôlés a été de 85%, 87% et 78% pour 2013, 2014 et 2015, respectivement, bien que

l'enrôlement annuel ait décliné de 10 724 à 6288, puis à 3749. Le suivi total en personnes-années (py) a été de 27 806, avec des pertes de vue de 40 pour 100 py. La probabilité cumulative de rétention dans le NSEP a été de 66% à 12 mois, de 45% à 24 mois et de 26% à 36 mois. Des taux de pertes de vue significativement plus élevés sont survenus chez les patients âgés de 15 à 24 ans ou ≥50 ans, de sexe féminin, transgenre et d'un groupe ethnique autre que malais.

**Conclusion :** La rétention annuelle des nouveaux PWID dans le NSEP a été impressionnante, bien que l'enrôlement ait décliné sur les 3 ans de l'étude et que les pertes de vue cumulées aient été élevées. Une meilleure compréhension de ces résultats du programme est requise.

**Marco de referencia:** El programa nacional de intercambio de agujas y jeringuillas introducido (NSEP) por organizaciones no gubernamentales en Malasia.

**Objetivos:** Describir la inscripción, la permanencia y las características de las personas consumidoras de drogas inyectables (PWID) que participaron en el programa NSEP entre el 2013 y el 2015.

**Método:** Fue este un estudio retrospectivo de cohortes.

**Resultados:** Se inscribieron en el programa 20 946 PWID, cuya edad promedio fue 38 años. La mayoría era de sexo masculino (98%) y de etnia malaya (92%). Se practicó el seguimiento de 20 761 personas. La tasa anual de permanencia en el programa de los recién inscritos fue 85% en el 2013, 87% en el 2014 y 78% en el 2015, pero la tasa inscripción anual disminuyó de 10 724 a 6288 y 3749 personas,

respectivamente. Se logró un seguimiento total de 27 806 años-persona (py), con una pérdida durante el seguimiento de 40 por 100 py. La probabilidad acumulada de permanencia en el programa fue 66% a los 12 meses, 45% a los 24 meses y 26% a los 36 meses. Las pérdidas durante el seguimiento fueron significativamente mayores en el grupo de 15 a 24 años de edad o a partir de los 50 años, en las mujeres, las personas transgénero y los grupos étnicos diferentes al malayo.

**Conclusión:** La tasa anual de retención de las PWID recién inscritas en el programa NSEP fue sorprendente, pese a que las inscripciones disminuyeron durante los 3 años y las pérdidas acumuladas durante el seguimiento fueron altas. Es necesario ampliar la comprensión de estos resultados programáticos.